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**Cancer and Serious Mental Illness – Patient, Caregiver and Professional Perspectives:
study protocol.**

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Conflict of interest

There is no conflict of interest to declare.

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TITLE: Cancer and Serious Mental Illness – Patient, Caregiver and Professional Perspectives: Study Protocol

ABSTRACT

Aim: To explore the experience of serious mental illness and cancer from the perspective of patients, significant others and health care professionals involved in their care.

Background: Serious mental illness is associated with poorer cancer outcomes. Those suffering from this comorbidity receive fewer specialist interventions and die earlier than the general population. Prior qualitative research in this area has comprised of a single study focussing on healthcare professionals, and there is little evidence regarding the experiences of patients and caregivers.

Design: A qualitative exploration using approximately 36 semi-structured interviews.

Methods: Semi-structured digitally recorded interviews conducted with: adults living with serious mental illness and diagnosed with cancer; those providing them with informal support and care; and healthcare professionals. Questions will focus on the experience of having cancer and serious mental illness or caring for someone with this comorbidity, experiences of healthcare, and priorities for patients and carers. Framework analysis will be used. Research Ethics Committee and Trust Research & Development approval was obtained. A steering group comprising six people with experience of either cancer or mental illness provided feedback and ratified the patient information sheets and interview schedules.

Discussion: There is a paucity of research addressing stakeholder perspectives on the experience of cancer and of cancer services for people with serious mental illness. Dissemination of findings will inform practice relating to the care of an often neglected population, informing better support for their significant others and the professionals involved in their care.

Summary Statement - Why this study is needed:

- People with serious mental illness experience poorer cancer outcomes than the general population, with mortality rates around double those for patients without mental illness. There are indications that this is linked to service-related factors.
- There has been no research that directly consults patients with comorbid cancer and serious mental illness, or their informal caregivers, about their experiences of cancer and of cancer care. There has only been one study directly consulting healthcare professionals about this issue.

Keywords: Serious mental illness, cancer, comorbidity, nursing research, nursing, multidisciplinary

INTRODUCTION

Cancer affects a growing swathe of the world population due to advances in detection, improved treatments and an ageing population in many countries, with an expected global increase in cases of approximately 70% in the next twenty years (WHO 2015). In the United Kingdom, ‘Improving Outcomes: A strategy for cancer’ (Department of Health 2011) lists the reduction of inequalities in cancer services and outcomes as a key aim. One group suffering inequalities is the long-term mentally ill. The 2010 National Cancer Patient Experience Survey showed that those respondents with a long term mental health condition (2% of those surveyed, n=1184) reported less positive experiences of cancer care (Department of Health 2010). Cancer can have a significant impact on mental health post-diagnosis, and research into psychological problems such as anxiety and depression as a result of cancer dominates publications (Purushotham *et al.* 2013).

This study operationally defined ‘serious mental illness’ (SMI) as: schizophrenia, other non-organic psychoses, and major affective disorders including bipolar disorder and major depressive disorder (Kisely *et al.* 2012; Tosh *et al.* 2014). Estimates of the lifetime prevalence for serious mental illness range between 2-3% of the population (Perala *et al.* 2007; Hardoon *et al.* 2013). Serious mental illness is associated with poor physical health and excess mortality (Phelan *et al.* 2001; Lawrence & Kisely 2010), with a study of serious mental illness patients under the care of the South London and Maudsley Trust finding life expectancies eight to seventeen years less than the general population (Chang *et al.* 2011). In relation to physical illnesses, increased rates of cardiovascular disease, respiratory disease, diabetes and Human Immunodeficiency Virus have been observed in this cohort (Robson & Gray 2007). The physical health of people with serious mental illness is being taken increasingly seriously – for example, National Health Service England have introduced a financial scheme whereby Trusts will be paid for assessing patients’ lifestyle and physical health indicators (NHS England 2014).

Background: Cancer incidence in people with serious mental illness has been a topic of international debate for more than a century (Gulbinat *et al.* 1992; Lichtermann *et al.* 2001), but there is now a general consensus that incidence is broadly similar to that of the general population (Irwin *et al.* 2014). Mortality rates, however, are around double those for patients without mental illness (Batty *et al.* 2012). Reasons suggested for the increased mortality rate for patients with serious mental illness and cancer include late presentation, and reduced usage of interventions such as surgery, chemotherapy or radiotherapy (Desai *et al.* 1999; Irwin *et al.* 2014). Some cohort studies (Hwang *et al.* 2012; Faratsapour *et al.* 2013) highlight the impact of psychiatric symptoms on noncompliance and disruptive behaviour among patients, while Sharma *et al.*’s 2010 United Kingdom study of a similar cohort (breast cancer patients with schizophrenia) found their serious mental illness symptoms did not adversely impact treatment. People with serious mental illness who develop cancer also experience disconnections between services and difficulties complying with treatment (Howard *et al.* 2010; Batty *et al.* 2012; Sinding *et al.* 2013; Kisely *et al.* 2013). People with serious mental illness are often excluded from cancer research and their voices are rarely heard in health

research generally (Irwin *et al.* 2014). The literature review undertaken for the study found that the bulk of papers dealing with comorbid cancer and serious mental illness focussed on schizophrenia, with much less attention paid to bipolar disorder or major depression.

Case studies involving people with serious mental illness and cancer illustrate some factors that may impede care. For example, patients who display unusual behaviour and self-neglect may provoke frustration and even anger among doctors (Cole & Padmanabhan 2012). Additionally, there is a consensus that stigma associated with serious mental illness may result in suboptimal treatment for cancer: stigma may result in the desire of health care staff to avoid more difficult patients, which may reduce quality of care (Schwartz *et al.* 1998; Irwin *et al.* 2014). Sinding *et al.* (2013) studied the process of care for people with serious mental illness who were diagnosed with cancer, from the perspective of social workers. Those interviewed reported that patients were discredited as witnesses to their own bodies and sometimes inappropriately referred back to psychiatric services. Three studies (Morris & Sullivan 1995; Elkhuizen *et al.* 2006; Sinding *et al.* 2013) describe improved relationships after a cancer diagnosis. Sinding *et al.* (2013) described this as their most striking finding; they suggest that cancer diagnosis (not uniquely among physical illnesses) is socially constructed as entitling the patient to resources and care often denied to those with serious mental illness, resulting in increased support from family members and healthcare staff.

The proposed research aims to explore the perspectives of people with pre-existing serious mental illness who develop cancer, their experiences of having cancer and interactions between cancer and mental health services. Patient perspectives will be triangulated with the views of their significant others and health professionals involved in their care. The existing preliminary evidence described above, relating to increased risk of mortality, will be further explored from a new perspective in the proposed research. This research will provide important insights that will benefit service delivery to patients with SMI. While this is particularly relevant locally to the National Health Service in the UK, it also has global relevance given the prevalence of serious mental illness worldwide.

THE STUDY

Aims: This study will explore the experience of serious mental illness and cancer from the perspective of patients, their significant others and health care professionals involved in their care. It will address the following research objectives:

- To understand the experience of key patients living with a pre-existing diagnosis of serious mental illness who then receive a diagnosis of cancer
- To understand the experience of caring for someone with a pre-existing serious mental illness who then receives a diagnosis of cancer
- To understand the experience of healthcare professionals who have worked with key patients

- To identify any additional support needs and examples of good practice that may inform future care delivery

Design: This study will use a qualitative research design that acknowledges that the researcher intends to study individuals' perspectives on the world (Parahoo 2006; Green & Thorogood 2009), with symbolic interactionism as the underpinning theoretical approach. Symbolic interactionism is based on the following premises: when people interact with their environment and other people, they attach meanings to those interactions and this guides their behaviour (Blumer 1969; Porter 1998). Symbolic interactionism can be used to examine the ways in which cancer impacts on individuals' relationships with their social world and their self-perceptions or 'self meaning' (Fife 1994, p10), and this can also be applied to mental illness. This theoretical approach can help illuminate the ways in which people relate to those perceived as living with mental illness. Serious mental illnesses are equally psychological disorders and an interpersonal phenomenon. A defining feature of serious psychiatric symptoms is that they represent thoughts and behaviours that other people cannot relate to, due to the inability to 'role-take' and understand their perspective (Rosenberg 1984). Understanding the processes by which the different participant groups included in this study attach meanings to their interactions with others may help to understand phenomena as varied as late cancer diagnosis or perceived challenges posed by serious mental illness patients in physical healthcare settings. Semi-structured interview questions will focus on eliciting the meanings the various participant groups will have attached to their experiences of (dis)engaging with NHS treatment, or providing treatment. Figure 1 below shows how symbolic interactionist concepts may be used to explore attitudes to healthcare in the case of patients with comorbid cancer and serious mental illness. The experience of having cancer and mental illness is influenced by interactions with healthcare services and professionals. This then impacts on the way the individual interprets their social world and self meaning, which influences their behaviour towards health services.

[see Figure 1]

Methods: 36 semi-structured interviews will be carried out to garner rich accounts of participants' experiences and ascertain emergent themes (Green & Thorogood 2009). A steering group has been established to provide ongoing input and consultation on designing the research and interpreting, validating and disseminating the findings. This group includes the researcher and supervisor; a nurse with oncology experience; and four individuals who variously have personal experience as cancer patients, carers or mental health service users. Individual members of the steering group have also assisted with practice interviews.

Operational Definitions: The following operational definitions are being used in this study:

Key patients (KPs): Individuals aged 18 years and above living with SMI and diagnosed with cancer in the past five years.

Significant others (SOs): Family members or friends aged 18 years and above, who are perceived by the Key Patient as providing informal support and/or care. Significant Others who have been bereaved between one and five years ago will also be interviewed.

Healthcare professionals (HCPs): Professionals employed by the National Health Service (to provide cancer-related or psychiatric and psychosocial care and support) or voluntary sector mental health services (to provide psychosocial support).

Interviews: All interviews will be conducted face-to-face lasting for approximately one hour, and will be conducted at a location suitable for participants. Interviews will be conducted firstly with Key Patients and Significant Others (Stage 1). The interview schedule has been developed by the researcher, informed by the literature and refined by the steering group, and focuses on a number of broad areas (Riessman1993), with introductory and closing questions. Interview schedules will ask Key Patients about their mental health history, their experience of cancer and cancer treatment, their priorities before, during and after treatment, and their perceptions of healthcare professionals. Significant Others will be asked similar questions relating to their caregiving role; questions for bereaved Significant Others will additionally enquire about end-of-life care and the role of mental health services. The findings from Key Patients and Significant Others will inform interviews with Healthcare Professionals (Stage 2), with input from the steering group. All interviews will be digitally recorded.

Setting: The study will be undertaken in Northern Ireland. Key Patients, Significant Others and Healthcare Professionals will be recruited through key voluntary agencies and a regional Health and Social Care Trust.

(see Table 1)

Key Patients who meet the inclusion criteria in Table 1 will be recruited via Mental Health services in a Health and Social Care Trust within Northern Ireland and the voluntary sector. Gatekeepers will be team leaders and local managers, respectively, and will assist in identifying Key Patients. Key Patients will be given an information pack (comprising an information sheet, a cover letter and a consent form) informing them about the research and providing the researcher's contact details should they wish to participate. If patients have a lay person who provides care for them, they will be asked to consider passing on an information pack to this person. Where possible, gatekeepers will also identify eligible bereaved Significant Others, who will be sent an information pack including a cover letter from the gatekeeper. Gatekeepers from Mental Health and Cancer services within the Trust, and the voluntary sector, will be asked to make information packs available to all staff. Professionals who are eligible to take part can then contact the researcher directly. Once the Key Patient or Significant Other has contacted the researcher, contact details will be taken by the researcher. If contact is broken thereafter, the researcher will make one additional telephone contact with the person concerned in order to establish whether they wish to

continue in the research. There will be no need for further contact between the researcher and gatekeeper, except to establish how many information packs have been given out.

Only those who have received or given help for serious mental illness and cancer from a statutory or voluntary organization within the last five years are eligible to participate. This is to ensure the research is relevant to current service provision. Former caregivers of a deceased person will only be interviewed if the person died more than one year but less than five years from the time of contact, based on ethical considerations (Beck & Konnert 2007). The rationale for including bereaved caregivers is that the exploratory approach of the study demands a broad range of stakeholder perspectives. The high mortality rate among patients with serious mental illness and cancer also suggests that interviewing bereaved caregivers may be an important means of gaining information about patients. Due to the anticipated small sample size, convenience sampling will be used and all potential participants will be invited to take part in the study (Lo-Biondo Wood & Haber 2010).

Data Collection: The researcher will seek to carry out approximately 12 interviews with each group (Key Patients, Significant Others, Healthcare Professionals). Interviews continue until point of data saturation, meaning the point at which new data produces little or no change to the themes generated (Guest *et al.* 2006). In total approximately 36 interviews will be conducted. Initial meetings will be arranged with Key Patients and Significant Others to build rapport, explain the research, clarify consent, and address any potential concerns.

Data Analysis: Framework analysis (Spencer *et al.* 2014), which is appropriate for practice-oriented findings as it seeks to preserve the integrity of respondents' accounts, will be used to analyse the data. The researcher will become familiar with the data, develop a coding scheme, compare cases and chart the data according to the thematic content (Green & Thorogood 2009) with a view to making practice-focused recommendations. Analysis will focus on the ways in which interviewees interpret their interactions with themselves and others, and on the social relationships embodied in these interactions (Porter 1998).

Ethical considerations: Ethical Approval has been obtained from the Office for Research Ethics Committee, Northern Ireland (05.01.15, 14/NI/1134) and Trust governance has been secured (03.03.15). The research will adhere to the Research Governance Framework for Health and Social Care, and the Good Clinical Practice Guidelines (Department of Health 2005).

Informed consent: All participants will be provided with user-appropriate information packs prior to contacting the researcher. Further details or clarification can also be provided when individuals contact the researcher. Participants will be asked to sign consent forms. Informed consent is an ongoing process and open to renegotiation (Munhall 2012), and participants will be informed they can stop at any time.

Anonymity and confidentiality: Transcripts will be kept for three years. Audio recordings will be securely deleted once they have been transcribed and checked. Identifying data will be kept separated from individual transcribed accounts through the use of personal

identification numbers (PIN). Personal Identification Numbers will allow for traceability should a participant wish to withdraw at a later stage. All records will be kept on a password protected computer in a locked office. Where data needs to be transported a secure portable device will be used and data will be held in password protected electronic files. Paper records will be locked in a filing cabinet in the supervisor's office. It will be made clear to participants that if they choose to withdraw from the study after data analysis is complete, it will not be possible to remove their data, but their information will remain confidential and their real names will not be used. The principles of the Data Protection Act 1998 will be adhered to (Information Commissioner's Office 2015).

Welfare of participants and researcher: This research is sensitive due to the topic and the vulnerable adult status of some participants. The researcher will stop an interview if a participant shows signs of distress (e.g., agitation or tearfulness). The interview will not re-start until the participant agrees and the researcher is confident that the participant can continue without further distress. If the participant chooses to withdraw, their permission will be sought to use material already gained; if permission is not given it will be confidentially disposed of. The researcher will also be mindful of the possibility of fatigue for those patients with advanced illness. Participants will not be interviewed if they lack capacity to understand the questions asked or to provide informed consent. This will be judged by gatekeeping professionals in the first instance. Following the interview, participants will be provided a support pack containing contact details of voluntary and statutory organisations that may provide additional support, for example crisis helplines and bereavement services.

The researcher recognises that the Key Patients, and potentially some Significant Others, can be considered vulnerable adults. Following Department of Health, Social Services and Public Safety guidance, this is defined as an adult "who is, or may be, unable to take care of ... or protect him or herself against significant harm or exploitation", due to mental health problems, disability, or physical impairment (DHSSPS 2014, p3). Should the researcher have reason to suspect that any such harm has taken place, he will follow the guidance for staff provided by the Department of Health, Social Services and Public Safety. This will include reporting the matter to the primary supervisor and the relevant Adult Protection Coordinator for the Trust or voluntary sector organisation. The 'Vulnerable Adult Abuse Report Form' (Volunteer Now 2013) will be used in such an event.

An interview will be stopped if a participant displays unsafe behaviour. This will include self-harming behaviour or aggression directed at others. A lone worker policy will be adopted to ensure researcher safety. This policy ensures that a responsible person (usually a PhD supervisor) will monitor the movements and whereabouts of the researcher at the time of scheduled interviews and that appropriate action is taken if there are any concerns. The researcher has ten years' experience working with adults with multi-complex needs, and has undergone training in qualitative research methods as part of a Masters' module at Queens' University Belfast.

Rigour: The use of symbolic interactionism as a theoretical approach necessitates an approach to rigour which acknowledges the subjectivity of respondents' accounts and does not seek to establish a central 'truth'. The approach to rigour used in this study must necessarily demonstrate that data has been gathered and analysed with integrity, whilst acknowledging multiple perspectives and constructions of reality. An audit trail of the process and the data, keeping a reflective diary, anonymised interview transcripts and notes will ensure the research process has been conducted honestly and that the authenticity of the data can be verified (Lincoln and Guba 1985). The value of symbolic interactionism as an underpinning theory will be assessed by its ability to make sense of the data gathered during the study. The analysis will focus on convergence and divergence between cases to test emerging theory. Furthermore, data triangulation - in this case, the use of data about a given topic from a number of different sources – will show whether or not similar themes are addressed by KPs, SOs and HCPs. The researcher will demonstrate evidence of transferability, or applicability to other settings by giving 'thick description' (detailed information) about the context and diversity of viewpoints in which the research was carried out. By this means, the credibility of the research will be maximised as participants' realities can be clearly conveyed to the reader (Denzin 1989).

DISCUSSION

Some practical issues have been recognized in relation to this research. Semi-structured interviews were chosen rather than unstructured interviews. Themes such as stigma, late presentation and fragmentation of services have arisen from the literature (Irwin *et al.* 2014) and therefore a semi-structured interview allows these topics to be covered and the interviewee to determine their importance (Green & Thorogood 2009). It is the intention of the researchers to keep Key Patients at the centre of the research. The researchers are mindful that the voices of people affected by mental illness have been excluded from much research (Rose & Beresford 2009). For this reason, the inclusion of Significant Others (where the Key Patient is living) is entirely dependent on the consent of the Key Patient. The use of a steering group will also help to keep the research focused on the needs of the population it is intended to help, as will the fact that the views of Key Patients and Significant Others will inform the interview schedule used for Healthcare Professionals.

To recognize and explore the needs of people with serious mental illness and comorbid cancer, research is needed that takes into account all serious mental illness, not just schizophrenia, which has so far dominated the literature (Callaghan *et al.* 2013). Research is required that directly seeks the perspectives of the patients concerned (Irwin *et al.* 2014). Serious mental illness and cancer is an under-explored area, particularly in terms of the lived experience of patients (Howard *et al.* 2010). So far there has been *no* research addressing the perspective of patients with serious mental illness and cancer, or their informal caregivers, on their experience of cancer and of cancer services, and only one study (Sinding *et al.* 2013) of the perspectives of professionals on this issue. A study that sought the perspectives of

patients on their experiences of having cancer and interactions between cancer and mental health services and triangulated them with the views of their significant others and professionals, could shed much light on the needs of this particular group. Such research would build on recent, but so far tentative, findings relating to the impact of stigma, the discrediting of patient experience, and the social construction of cancer and mental illness (Sinding *et al.* 2013, Irwin *et al.* 2014), and on research interviewing people with serious mental illness and other health conditions, such as diabetes (El-Mallakh 2006).

Limitations: We perceive some study limitations. Due to time and resource constraints, only English-speaking participants will be eligible, potentially limiting the range of views explored. Another limitation is that it is not possible to identify all Key Patients in Northern Ireland. This is due to the fact that in the United Kingdom or devolved regions, no database exists which could identify those affected by comorbid serious mental illness and cancer. The fact that the study seeks to triangulate data by interviewing major stakeholders (patients, caregivers and healthcare professionals) will also help reduce bias, alongside gaining a wider understanding of the phenomenon. The inclusion of bereaved caregivers and healthcare professionals, in particular, will allow information to be provided about a broader range of patients than can be accessed for direct interviews.

CONCLUSION

Dissemination of findings will make a significant contribution to international knowledge and understanding in this under-researched area. Findings will be used to inform education, practice and policy, and to inform and better support significant others and professionals involved in the care of people who have serious mental illness and cancer. The study will contribute to the body of research concerning comorbid physical and psychiatric illness. The process of the study will highlight ‘what works’ in terms of accessing and interviewing adults with comorbid physical and mental ill-health and will therefore provide a foundation for further qualitative work in this field .

Author contributions: All authors have agreed on the final version and meet at least one of the following criteria [recommended by the International Committee of Medical Journal Editors (http://www.icmje.org/ethical_1author.html)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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TABLES AND FIGURES

Participant selection and recruitment

Table 1: Inclusion and Exclusion Criteria

	Inclusion	Exclusion
Stage 1: Key patients and significant others		
Key Patient	<p>Over 18</p> <p>Diagnosed with cancer in past 5 years, and aware of this diagnosis</p> <p>Living with a serious mental illness(as defined by gatekeeper)</p> <p>May have diagnosis of substance misuse, as well as serious mental illness and cancer</p> <p>May be in receipt of palliative care</p>	<p>Non-English speaking</p> <p>Diagnosis of dementia</p> <p>Lack of capacity to consent to be interviewed</p> <p>Diagnosis of mental illness was subsequent to cancer diagnosis</p>
Significant other	<p>Informal carer for Key Patient; eligibility as such to be determined by Key Patient</p> <p>May be a former Significant Other for a Key Patient who is deceased</p>	<p>Key Patient (living) is not part of study</p> <p>Key Patient (living) does not consent for SO to take part.</p> <p>Key Patient is deceased and death was less than one year or more than five years before time of contact.</p>
Stage 2: Healthcare Professionals		
Cancer	<p>Healthcare Professional employed by cancer services, who has worked with at least one key patient in the past five</p>	

years

Mental Health Statutory Sector	Healthcare Professional employed by mental health services who has worked with at least one key patient in the past five years
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Mental Health voluntary sector	Healthcare Professionals and other staff employed by voluntary sector mental health services to provide psychosocial support, who have worked with at least one key patient in the past five years
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Design

Figure 1: Patients with comorbid cancer and SMI: relationship with healthcare services

